

March 14, 2018 - Education Committee Public Hearing Testimony

Dear Chairman Fleishman, Co-Chairs Boucher and Slossberg, Ranking Member Lavielle and Education Committee Members:

I am one of the advocates who initiated the legislation that created the Task Force charged with studying the issues around food allergy management in Connecticut schools. I served on the task force and contributed to the comprehensive report the Education and Public Health Committees were presented with upon completion of that work. I am also the mother of two 12 year old boys who both have life threatening food allergies and who attend Fairfield Public Schools. I am actively engaged with the food allergy community both here in Connecticut and across the country.

I am writing in support of **Raised Bill 5452**, An Act Concerning the Recommendations of the Task Force on Life Threatening Food Allergies in Schools, but ask that you consider the following to strengthen the legislation.

Regarding Section 1:

The CT Guidelines on the Management of Life-Threatening Food Allergies are not in line with the current CDC Guidelines and Allergy and Anaphylaxis Guidelines and leaves school districts and students at risk. Guidelines must be updated to reflect current standards of care and current legal standards and be pushed out to all Superintendents and Boards of Education for immediate implementation (via circular letter). Legislation language should be amended to require that the guidelines and training modules be updated at least biennially or as needed (if sooner). The goal here is for all districts to operate off the same medically approved information, regardless of individual resources and availability of nursing staff. It is acceptable for districts to vary in implementation tactics for certain aspects of managing or accommodating students with life threatening allergies, depending on their population needs and resources. However it is not acceptable for adherence to medical protocol and federal disability and discrimination laws to vary from district to district, building to building, classroom to classroom or school bus to school bus.

It is imperative that the guideline revision explicitly include protocols for the identification and evaluation of students with life-threatening food allergies for protections and accommodations under Section 504 of the Rehabilitation Act of 1973 and/or IDEA, in accordance with CT's Child Find law and the ADA, so that will become routine practice within school districts. Too many students are going without formalized accommodation and health care plans which leaves the door wide open for exclusion, error and injury. An emergency care plan, provided by the child's doctor is insufficient as a means to allergy management.

Regarding Section 2:

I support this section as it relates to the Healthy and Balanced Living Curriculum but suggest including language around training/ teaching on dietary restrictions, cross-contamination allergen avoidance protocols and allergen identification.

Regarding Section 3:

As it relates to transportation of students with life threatening food allergies, it is important to remind the committee that transportation is a related educational service and that students with recognized disabilities are entitled to equal access to that service, in the same manner as non-disabled peers.

It is imperative that the state immediately develop and disseminate a standard protocol for the safe transport of students with documented life-threatening food allergies which will be uniform across all CT school districts. The definition of “safe” here must be made clear – and must address both allergic reaction preventive strategies and medically prescribed emergency response.

Epinephrine is THE first line treatment for anaphylaxis. It is the only treatment that can halt an allergic reaction. Prompt administration of epinephrine is crucial, as delay in administration has been proven over and over again to be THE most significant contributor to permanent injury or death. Epinephrine auto-injectors are designed for use by everyday people. I taught my children how to administer at age four. An allergic individual in the midst of an anaphylactic reaction may not be able to self-administer epinephrine.

We must immediately abandon the current protocol of having bus drivers pull the bus over, call dispatch who will then call emergency services, and then sit and wait. Intervention must be swift.

Therefore in addition to provisions addressed in current language the committee needs to add: *the provision that an adult (school personnel or transportation personnel), who has received the required training, will be available on each bus carrying a student/students with life threatening allergies and will administer epinephrine in the event of an allergic reaction.*

Each district can make the determination as to how they can best implement this requirement based on student population and local resources. But the fact remains that SOMEONE on the school bus must be able to implement a student's emergency care plan and administer epinephrine to save their life, should an allergic reaction occur during school transport. It is not an ideal scenario, we understand. No one wants their child to react on the school bus. But it does happen and we cannot allow deviation from standard and required medical protocol. To do so would constitute negligence (in the case of a student with a documented allergy) and the liability needs to be considered. While the committee has considered providing immunity for bus drivers within this bill (which is unnecessary according to the CT Trial Lawyers Association testimony) what should really be considered is liability for standing by and doing nothing when a

simple intervention can save a life. If the bus driver follows existing protocol, they have already pulled over the bus, and are contacting dispatch. The only additional step needed is the administration of the epinephrine. It takes mere seconds. It must be required. If we truly are to consider the bus driver in this situation, we must give them the tools and training they need to be able to respond. Otherwise they, like the student, are left helpless.

Vetted and endorsed training modules on anaphylaxis and medication administration are readily available and in most cases free. This training should be made part of the bus company/driver training requirements and could possibly be made part of the process for obtaining the special license needed to become a school bus driver.

Finally, I ask that you add a critical missing piece to this legislation. We absolutely must allow students to self-carry their epinephrine auto-injectors without the requirement that they be capable of self-administration. At present these two items are tied together under the medication administration regulations and it must be corrected. Student competency to self-administer epinephrine is not solely based on developmental capability and would be compromised by the effects of anaphylaxis. Expecting someone to self-administer this medication while suffering respiratory, cardiovascular, gastrointestinal, cognitive and other symptoms of anaphylaxis is unrealistic and irresponsible. It is akin to asking someone having a heart attack to use an AED on themselves. These students must ALWAYS have access to their epinephrine. Before and after school, nurse offices are locked up along with the medications, so self-carry for before and after school activities is vital. The same applies to off-premise activities. And of course it applies on school provided transportation.

Please address this gap in safety with this suggested language:

All local and regional Boards of Education create a provision that students with a diagnosed food allergy may self-carry their epinephrine auto-injectors on their person with written consent from the student's medical provider and parent, without the requirement to self-administer, for the prompt administration of life-saving medication. No local or regional board of education may prohibit or restrict the time and location of the right to self-carry auto-injectors by children with life-threatening food allergies who have a written order from a physician or an advanced practice registered nurse and consent of the parent. This statute applies to the school day, transportation and extra-curricular activities. The Commissioner of Education, in consultation with the Commissioner of Public Health, shall develop guidelines for policies and practices with respect to safe-handling of self-carried auto-injectors without self-administration by children pursuant to this section.

The issues before you are related to the safety and inclusion of food allergic students. As we all hear repeated again and again, NOTHING should come before student safety. I could not possibly agree more. That being said, it is important to stress that for a food allergic child risk is ubiquitous. It is for that reason that parents of food allergic children need to be vigilant managing their allergies and the potential risks across all environments and at all times. There simply is no respite. Our children's medical protocol is strict avoidance of allergens, always

having access to two epinephrine auto-injectors and prompt administration of that epinephrine at the first signs of a reaction. When we hand our children over to their schools every morning, the school assumes not only the education that child, but also their care. And not until that child is handed back to that parent each afternoon does that responsibility release.

Thank you for your consideration and action on these important issues.

Jessica Curran